Civil Society Response to Accessibility Standards for Healthcare of Persons with Disabilities

*Drafted by Rising Flame*

**Introduction**

We, the civil society members from across India, would like to take this opportunity to appreciate the government for releasing an important manual around accessibility standards for healthcare of persons with disabilities in the country. Despite The Rights of Persons with Disabilities Act, 2016 (RPD), the ratification of the United Nations Convention on Rights of Persons With Disabilities, and after India being a signature to the Sustainable Development Goals, persons with disabilities are struggling to access healthcare, which was spotlighted and further exacerbated during the pandemic. To ensure nondiscrimination as a legal and constitutional right, larger systemic and structural changes need to be facilitated and instituted. To achieve this, the ‘Accessibility Standards for Healthcare’ manual is extremely important. Therefore, it is also imperative that the manual be representative and inclusive of all 21 disabilities recognised in the RPD legislation and to have a nuanced definition of accessibility and more robust standards in implementing it.

After a national consultation for persons across disabilities facilitated by Rising Flame and an open input process, we have drafted the following recommendations to strengthen the document published by the Ministry of Health and Family Welfare. An important manual of this nature should be drafted with participation from persons with disabilities and experts from the disability community.

- The manual should institute an accountability mechanism as well as a short term and long term implementation strategy including a feasible timeline for these measures to be put in place.
The manual should clarify the budgetary allocation which is mandatory to make significant changes required in healthcare access.

The manual should focus and include accessibility needs of all persons across all disabilities including those with high support needs, and not have more weightage on visible or otherwise accepted disabilities.

The manual should actively include and account for the unique accessibility needs of and barriers faced by women and gender marginalised persons with disabilities.

The manual should include the accessibility needs of children with disabilities.

The manual should have language and terminology with regards to disabilities in strict compliance with UNCRPD and the RPD Act. The rights based language and terminology should be used uniformly throughout the document. Replace words like hearing problem, speech problem, mental problems, psychological / psychiatric disability with rights based language of hearing disability, speech disability, psychosocial disability.

Many of the recommendations of altering equipment and infrastructure are urban in nature. Given the context of our country and the high prevalence of disability in rural areas, the manual should have specific implementable solutions to ensure access to health care at village, taluka and district levels.

Over 70% of the healthcare services in India are provided by the private sector. Therefore the standards should be mandated for both existing and upcoming government facilities as well as private health facilities.

As an important document on access to health care, it should also make provisions to support persons with disabilities navigating the healthcare systems and medical facilities when they play the role of caregivers and attendants to their children, parents, family members, and others.

For ease of navigation the recommendations have been clustered into 5 groups to ensure full access and accessibility of healthcare spaces, systems and services.

**Infrastructure Accessibility**

For ease of understanding, this area will be split up into sections.

**Environmental Accessibility:**

(This refers to areas around all medical facilities.)

- **Clearly designated parking and loading zones** for individuals with disability to be available around medical facilities. The same to be made visible on navigation systems as well.

- **Adequate accessible lighting and contrasting lighting** in and around areas leading to the medical facility and/or parking zone in accordance with the relevant recommendations from British Standard EN 12464-1 and Lighting Guide 5 (produced by Society of Light and Lighting, UK)
Pathways to be **curbless with tactile markings** for ease of navigation on foot.

**Anti-skid flooring with tactile markings** in areas leading to the medical facility.

**All entry and exit points** to the hospital/medical college/medical facility to be **clearly marked** with sign boards and to be accessible across disabilities.

### Navigation Inside the Medical Facility:

- **Clear labelling** in simple language, large font, clear signages, and tactile markings on all floors and outside all rooms/clinics/entry/exit/washrooms/waiting rooms etc.
- **Elevators to be accessible** in terms of assistive devices like wheelchairs and crutches. They also must have braille markings and audio outputs for each floor.
- **Height adjustable and comfortable chairs** clearly designated seating in waiting rooms.
- An **accessible digital navigation guide** to be made available via an app or the website will help navigate the medical facility for individuals with sensory concerns and psychosocial disabilities.
- Provision of **human assistance for those with blind and low vision disabilities** and other disabilities to navigate the medical centres/hospitals.
- The **railings given for staircases and ramps** should extend a little below the step and should not end abruptly one step above.
- No pots/ornamental plants should be placed next to grab railings to prevent injuries during usage.
- **Clear information about the location of a quiet room** where children and adults with disabilities who experience sensory overload can go during the duration of the healthcare setting visit.

### Accessibility of Documents and Payment:

- **Accessible digital mediums** to be used in order to fill medical forms and consent-related documents.
- **All diagnostic reports (blood tests, sonography and ultrasound among others)** prescriptions, pre/post procedure instructions, **bills** to be made available on the same accessible digital medium.
- **Data privacy laws** to be taken into account when designing/administering such digital mediums to patients.
- **Ensuring that payment interfaces** and other such services are **accessible** across disabilities as part of digital infrastructure. For example, having an alternative to touch screen card machines, having talking ATMs in accessible locations, if any, within the medical centre.
Accessibility with Regards to Medicines and Medical Equipment:

- Equipment provided for **recovery/ monitoring** (e.g. thermometer, spirometer, Oxymeter, blood pressure machines, glucometers etc) must be made accessible.
- **Measuring cups** for liquid medication must have braille markings and/or audio outputs to enable self- consumption of correct dosage.
- Medicines to have **barcodes in universal formats and accessible with barcode readers**, to help blind and low vision users to scan to know details of the medicines procured including drug ingredients, side effects of medicines, recommended dosage etc.
- Design of **home tests** (COVID antigen test, pregnancy test etc) should be universally accessible, so that persons across disabilities could use them on an equal basis with others.
- **Essential healthcare services** for people with disabilities including physiotherapy, aqua therapy, should be made available from taluk and district level (CHC and PHC). Similarly district hospitals must be equipped with **equipment and skills** to provide calipers, prosthetics and crutches to reduce the additional cost of travel for people with disabilities.
- **Medical stores** should also be counted within the healthcare system and therefore should be fully accessible across disabilities.

Accessibility in Times of Emergency:
(This refers to emergency response service.)

- **Ambulances** should be accessible as per the accessibility standards laid down for public transport vehicles.
- **Maximum occupancy requirement** in an ambulance may require to be waived in cases of individuals with high support needs and/or intellectual disabilities to make way for interpreters and/or personal assistants to also be present along with one person.
- **Interpreter support must be available** along with ambulance services in case it is sought by deaf or deafblind people who might need support to communicate with the medical professionals in the ambulance.

Accessibility of Information & Communication

- **Websites** which have information related to healthcare should be fully accessible with adjustable font size, accurate colour contrast and access to screen reader for JAWS/talkback/refreshable braille device. Language must be simple, easy to understand and also demonstrated with use of images and sign language. Audio-video transcriptions and image descriptions should be available throughout the website.
- Digital medical platforms like **e-pharmacy, e-consults** should make all information/communication/announcements on their platforms in plain language and made available in a range of accessible formats including sign
language, braille, audio versions, text only and easy to read versions and in languages used by the local population.

- **All medical digital platforms** are mandated to design/develop online platforms in line with W3CAG ([web accessibility guidelines](#)).

- **Health settings which have TV screens** with informational content must make the content accessible in a range of accessible formats including sign language, braille, audio versions, text only, with captions and easy to read versions.

- **Health settings** like hospitals, clinics, primary healthcare centres must hire or empanel **fluent Indian Sign Language interpreters, including tactile interpreters** to support independent interaction of deaf persons with the doctors and other staff in the centre.

- Health settings must provide **text support** options or alternatives to verbal communication to deaf and hard of hearing persons accessing services and use of **Augmentative and Alternative Communication (AAC)** for others who may be non-verbal.

- **Teletypewriters** to be made available wherever possible.

- **All medical documents** (pre/post test or procedure guidelines, prescriptions, test results, medical notes, consent form, liability waiver etc.) be available in audio form, braille form, accessible electronic formats, in sign language.

- Information about **nearest grievance cell**, contact details for organisations that provide medical assistance or financial aid, social schemes etc. are available in multiple accessible formats as detailed above.

- **Informed Consent** for all medical procedures – from diagnostic tests to medications to surgery to any other medical therapy / procedure - should be mandated. For this consent forms and relevant instructions / information must be provided to the patient in an accessible format for full comprehension, and direct patient consent should be ascertained, especially for stigmatised disabilities like developmental disabilities, intellectual disabilities and psychosocial disabilities.

**During Disaster/Pandemic**

- Make **all communications/ information/ announcements regarding healthcare during a disaster/ crisis** in plain language and made available in a range of accessible formats including sign languages, braille, audio versions, easy to read versions and in languages used by the local population at the same time as it is available to the general population. The accessible information should be up to date and made available to even underrepresented groups among persons with disabilities such as the deafblind and persons with disabilities who continue to remain in group homes and institutions.

- **All available helplines** for healthcare services should be **fully accessible**. It should also have text based or message-based support available along with video support through sign language users.
Sign language interpreters or guides and other persons trained to support persons with disabilities should be treated as essential frontline workers and given the same level health and safety protection as other healthcare workers in the time of a disaster.

Personnel Training and Engagement for Accessibility

- **Disability specific sensitisation programmes** to be designed for doctors and other healthcare staff (nurses, ward boys, paramedic staff, chemist, security staff, admin staff) covering all aspects of a medical experience (appointment booking, locating the doctor, history taking, physical examination, non invasive and invasive tests, medication prescriptions, communication during surgeries/ child birth etc.) These programmes must be mandatory in nature and with frequent refresher courses.
- Extensive training to be provided on the **concept of consent** in the disability context, so that informed consent should be patiently and consistently sought during all medical procedures especially for **underrepresented or stigmatised disabilities like developmental, intellectual, and psychosocial disabilities.**
- Disability specific access requirements and **sensitisation training** to be provided to paramedics and mobile health staff (ambulance drivers, at-home physiotherapists, at-home phlebotomists etc.) that provide healthcare at home.
- RPD legislation **training to be mandatory** for all healthcare and social protection agencies, along with disaster management agencies at a national level.
- All **persons responsible for handling emergency response services**, including quarantine and testing centres, should be trained on the **rights of persons with disabilities**, and on risks and co-morbidities associated with persons with specific disabilities acquiring COVID-19.
- **Training provided** with regards to recognising violence, recording experiences, providing medical support to **victim-survivors of sexual assault** must include guidelines laidout in ‘Guidelines and Protocols: Medico-legal care for survivors/victims of Sexual Violence’ for persons with disabilities.

Home Based Medical Facilities

- **Home Based services to not be restricted** to medical services alone, but be expanded to include personal assistance services, elder care services, psychosocial services, blood transfusion, chemotherapy and child care services as well.
- **Expansion of psychosocial services at home** to include therapeutic support, occupational therapy, counselling, rehabilitation services among others.
- Vaccinations (Child immunisations, adult immunisations and COVID vaccines) to be emphasised as an important component of home based medical facilities to be made available to people with disabilities.
- Holistic healthcare packages to be deployed at community level for people with disability having high support needs.
- Essential screening tests like sonography during pregnancy, X-rays in event of injuries or secondary prevention etc. to be made available at home for people with disabilities.

**Social Protection and Healthcare Access**

- Disability certification process to be streamlined and implemented in alignment with RPWD Act 2016. Certification process to be available in a range of accessible modalities like online, and at-home along with the in-person process to make acquiring a certificate and accessing subsequent health schemes and services accessible.
- Disability certification status to be linked with UDID and both to be acceptable universally.
- Cashless health insurance schemes providing adequate health coverage across domains such as OPD cover, accident cover, critical Illness, assistive devices and services, home healthcare services, and maternity cover to be designed for persons with disabilities.
- Government schemes and health insurances to be designed specifically for individuals with high support needs that cover social, medical and emotional aspects of condition management.
- Using disability certification to identify disabled people through the panchayat system to link social security support systems, state level health schemes and for these to reflect disability related added costs and implement without taking away choice, consent and autonomy.
- Insurance accident covers must include costs or replacement if there is damage to hearing aid, cochlear implants, prosthetics during accidents.
- Strict guidelines on providing insurance to persons with disabilities, since insurance companies often deny insurance or charge high premiums resulting in further exclusion in accessibility to healthcare systems.
Drafted by:
1. Nidhi Goyal, Rising Flame
2. Pooja Menon, Rising Flame
3. Srinidhi Raghavan, Rising Flame

Inputs by OPDs, disabled activists, scholars and lawyers: (in alphabetical order of all attendees)

1. Abha Khetarpal, Cross the Hurdles
2. Adsa, SAMA - Resource Group for Women and Health
3. Akhil Paul, Sense International India
4. Anjali Vyas, MSSI
5. Anmol Diwan, Centre for law and social justice, Jindal Law School
6. Asha Hans, SMRC
8. Dr. Anubha Mahajan, Chronic Pain India
9. Dr Dipika Jain, Centre for law and social justice, Jindal Law School
10. Dr Marisport, Gujarat National Law University
11. Dr. Deepa V, Kodagu Institute of Medical Sciences
12. Kanika Agarwal, Independent Activist
13. Kavya Mukhija, Independent Activist
14. Ketan Kothari, Sightsavers India
15. Kim Fernandes, Researcher and Activist
16. Meenakshi Balasubramaniun, Center for Inclusive Policy
17. Mohammed Asif Iqbal, PwC
18. Natasha Agrawal, Jindal Law School
19. Nikita Sarah, Leprosy Mission
20. Pavan Muntha, Swadhikar
21. Poonam Natarajan, Vidya Sagar
22. Prabha Nagaraja, TARSHI
23. Raj Mariwala, Mariwala Health Initiative
24. Rakshita Shekhar, Independent Activist
25. Renu Addlakha, CWDS
26. Reshma Valliappan, The Red Door
27. Saudamini Pethe, AlFDW
28. Shampa Sen Gupta, Sruti Disability Rights Centre
29. Shruti Pal, PhD Student
30. Smitha Sadasivan, Accessibility and Inclusion Consultant
31. Subhojit Goswami, Leprosy Mission
32. Sumita, Latika Roy Foundation
Endorsed by:

1. Abdul Mabood, Director, Snehi
2. Abhishek Anicca, Independent Writer and Activist
3. Amena Kanchwala, Accessibility consultant, HCL Technologies
4. Amita Pitre, Independent Researcher and Development Practitioner
5. Amor Kool, Director, Centre for Accessibility in Built Environment Foundation
6. Amvalika Senapati, Deputy Director, Advocacy Shishu Sarothi
7. Ananya Pathak, Student, Kempaiah Retired professional, individual
8. Anavi Chander, Student, London School of Economics
9. Anita Ghai, Professor and Dean, Ambedkar University
10. Anwesha Bala Krishna Venkatesh, Hon President & Hon Convener CBR Global network, Indian Forum For Rehabilitation and Assistive Technology(IFRA) and Disability Rights Consortium(DRC)
11. Apoorv Kulkarni, Disabled professionals
12. Arnab Kumar Bhattacharya, Coordinator (Communication and Fundraising)
13. Ashish Goyal, Disabled professional
14. Banibrata Mahanta, Professor of English, Banaras Hindu University, Varanasi
15. Bapu Trust for Research on Mind and Discourse
16. Dipika Jain, Anmol Diwan, Natasha Aggarwal, and Srianusha Thotakura from Centre for Justice, Law and Society, Jindal Global Law School
17. Dr Anita Victorina Rego, Director PEARLS 4 Development Pvt
18. Dr Kavita Murugkar, Universal Design Specialist, Design Bridge Foundation
19. Dr Rajaram Subbian, Executive Director, Basic Needs India
20. Dr. Monica Gupta, Independent medical doctor
21. Dr. Neha Goyal, Independent Medical Professional
22. Dr. Rekha Gupta, Independent medical professional
23. Dr. Sandhya Limaye, Professor, Tata Institute of Social Sciences
24. Dr. V. Janaki, Disability rights activist
25. Gautam Chaudhury, Disability Development Worker
26. Geetika Sawhney, Student
27. Karnati Srinivas, Teacher, Visually challenged employees association, Telangana state KVJ
28. Dr Sumithra Prasad, Founder - General Secretary, DORAI Foundation
29. M. Srinivasulu, Present, Network of Persons with Disabilities Organisations (NPdO)
30. Mahima Nayar, Independent Researcher
31. Manasa Veluvali, Student
32. Mariwala Health Initiative
33. Mohit Khatanhar, Disabled entrepreneur
34. Mudita Jagota, Student
35. Nida Jamadar, Student, Nirmala niketan college of social work
36. Nitika Gupta, CODA
37. Pallavi Kulshrestha, Project Planning and Management Officer, Welfare Society for Persons with Speech and Hearing Impairment
38. Paresh Satra, Disabled entrepreneur
39. Pavan Muntha, CEO, Swadhikaar
40. Prabir Chatterjee, Doctor
41. Prachi Arora, CODA
42. Pratham, B C Student
43. Priya Varadan, Disability researcher/activist
44. Rachana Singh, Manager - Business Development, BASIX
45. Rajat Kumar, Indian Sign Language Teacher, WCPSHI
46. Rackhita Shekhar, Independent Activist
47. Reena Mohanty, Program Manager, Shanta Memorial Rehabilitation Centre
48. Reshma Valliappan, The Red Door
49. Rukmini Sen, Professor, Dr B R Ambedkar University Delhi
50. Samir Sethi, President, Indian Rett Syndrome Foundation
51. Sangeeta Rege, Coordinator, Cehat
52. Sangeeta Saksena, Co-founder, Enfold Proactive Health Trust
53. Sara Sharma, CODA Saswati Ghosh, Associate Professor, Economics City College, Kolkata
54. Saudamini Pethe, Trustee, Access Mantra Foundation
55. Sejal Dand, Development Worker, ANANDI
56. Shilpa Das, Professor, National Institute of Design
57. Shiv Raheja, Disabled entrepreneur
58. Sushma Luthra, Director-Event Planning & Logistics, CREA
59. Vanita N Mukherjee, Independent Researcher
60. Woman With Disabilities India Network
61. Yagna M, HoH deaf student
62. Zahra Gabuji, Project Co-Lead, Point of View